"ideal" physical and mental level shames those who cannot. Shame is visited on women with chronic illnesses for not getting better, or for not dying. The woman who does not fit social expectations of functioning is shamed by society, made to feel that she is worthless, disconnected from others, and is not accepted for who she is. Caron calls for a society where chronic illness is seen as part of life and where society accepts those with chronic illnesses as having a right to live with whatever accommodations are needed. In the process, she concludes, society will learn about living with chronic illness, which is part of life.

Power—who has it and who does not—is also mediated by social perceptions. Mary Delaney and Sandra Bell, in "The Complexities of Negotiating Power under Conditions of Chronic Illness," explore how women with chronic illnesses are negotiating power in their lives. They discuss their own situations as women with chronic illnesses and conclude, through the use of theory, that society itself, because it is organized as a patriarchal one, causes stressors that may lead to chronic illness. And, in the end, perhaps it is the stress of inequality on both the home front and work and the need to resist it that just wears woment out. Thus, many women with chronic illnesses continue to struggle with fatigue.

In "Crazy Talk: A Dialogue between Two Young Women about Depression," Mandy Fraser and Jennifer Matwee discuss how having depression affects their own views of themselves—they know how others perceive them in ways that are not usually positive.

They deconstruct the attitudes of a society that indeed has certain roles for young women to fulfill, and they conclude that through the process of dialogue for this article, they have empowered themselves from a feminist perspective to see that depression is an "identity" that is in flux and that depression is not a "label" that is static.

Sheilagh Grills and Scott Grills provide accounts of women's doubt about their chronic illnesses and their place in society in "The Social Construction of Doubt: Women's Accounts of Uncertainty and Chronic Illness." Doubt arises from the uncertainty of women who find that sometimes the medical profession's reading of their chronic illness is not their lived experience. There is also doubt about one's future plans, one's relationships with others, and the ability to continue doing things one enjoys. This doubt is part of living with chronic illness. The women experience uncertainty in their lives, but doubt in itself can provide hope that the chronic illness and life as it is currently may change in the future.

WATER WEARING ON A STONE
The Role of Shame in the Social Construction of Chronic Illnesses

Charlotte Caron

The narratives used in this chapter arise from interviews, correspondence, and dialogue with women who live with mental and physical chronic illnesses. These interviews were done as part of a larger project on loss and hope in women's lives. The full project, over an eight-year period, includes interviews and correspondence with 40 women. Some women asked to have their own names used; others were given pseudonyms by the researcher to provide anonymity. Using the methods of grounded research, women had the opportunity to describe losses in their lives, and offer resources for those who seek hope. Several women related stories about living with chronic illness and their dreams of the transformation of society into a place where people with chronic illnesses form part of the welcome tapestry of human existence rather than being seen as objects to be shamed, pitied, and treated with disrespect.

Elizabeth Richards (1997) relates an experience she had a few years into life with multiple sclerosis:

> It was one of those slow days when moving was difficult and I was using two canes. We were going into a store where I had seen a

> picture that I liked. Just after we entered the store, a man looked at me with one of those looks that is half way between pity and fear and said, "What happened to you?"
>
> I was humiliated. I felt like I was damaged goods. I never really remembered just what I said to him. I know that I never went to look at the picture, I just turned around and left the store.... (p. 54)

Liz describes being shamed. Shame arises as that painful self-consciousness in which we feel exposed to others and to ourselves as deficient, worthless, or contemptible (Fowler 1996: 92). In shame, we feel rejection, disapproval, or exclusion. Shame hurts. When we are shamed, we feel alone and disconnected while deeply desiring to be connected with others. Shame overwhelms us with a pervasive feeling of being a failure as a human being. Within North American society, chronic illnesses are socially constructed to shame those affected by them.

Chronic illness is both a physical and/or mental condition, and a social construct. The physical part—which usually involves diagnosis of a disorder in bodily functioning—is most often challenging. Discovering that one has multiple sclerosis, asthma, lymphoma, lupus, irritable bowel syndrome, environmental illness, or any other ongoing condition confronts one with new regimes for living and often a sharpened awareness of mortality. Living with chronic illness is not easy. It is inconvenient, frequently painful, full of loss, and full of rage. We have to put more effort into ordinary things, consider options and consequences more carefully, and make choices about our lives that most people with able bodies do without thought. But our society does not let it end there. Barriers to ordinary functioning arise at every turn. Some are physical; others come from social mores, attitudes, and the social structuring of relationships. We are taught through social conditioning to see things in certain ways. We see life through the eyes of our society and through the history, ideologies, and beliefs that have been passed to us. These ideas are created by those who hold power: those who hold power create our culture. For example, gender matters only if it is said to matter. Our culture could be constructed in ways that do not overtly and covertly teach children from early ages what girls should be like and do in our society, and that do not reinforce particular roles and behaviours as appropriate for women. Likewise, disability and chronic illness matter when society is designed to make them matter—for example, by creating inaccessible buildings and modes of transport; by calling people "stupid" when they do not hear well or speak clearly; by connecting value to the ability to be productively involved in full-time paid employment. Our views are socially constructed. Currently in North America, society is constructed in ways that give men (especially White, able-bodied, wealthy men) power and privilege, and that create systemic barriers for women (and specifically women with chronic illnesses and disabilities).

As I write this chapter, I am staying in a high school residence building at a summer writing course. When I arrived at my room, my roommate greeted me with a cheery smile and welcome. She said, "I hope you don't mind that I took the bed closest to the washroom."

"It's fine," I replied starting to organize my side of the room. She persists, "I don't walk well. I might as well just say it: I am not drunk. I just stagger a lot. I have MS."

"It's okay. I have spent time with others with MS, so it is familiar to me," I reply. Thoughts of friends who live with MS, and the irony of the writing I intend to do this week about chronic illness, fill my mind, but I move to the practical. I ask her not to use perfumes and other scented products and I tell her I have multiple food allergies. She says it is okay because she has a friend with a lot of allergies like me. I am relieved that the week with her will not create physical problems for me.

My next thought is that we were put together because we are the "special needs people," but it turns out that the organizers have not taken my less visible needs seriously. Although I asked that they consult the kitchen about provision of meals I could eat, they had not. Such disregard for physical needs makes travelling risky for me. I never really know whether the food available will provoke allergy or asthma attacks, cause irritable bowel syndrome flare-ups, or leave me feeling sick all week. Here the school's kitchen staff treat me with respect and make special food for me each day, but the conference organizers who have rented the space take no responsibility for meeting my needs.

My roommate gets the help she needs from others—pushing her wheelchair, help with meal trays, and the like. She symbolizes visible chronic illnesses with its resultant mobility disability. I signify the invisible, and have to advocate for myself at each meal. Two sides of the same coin: life with chronic illness.

My roommate and I are two people with different manifestations of chronic illness, and yet we have inklings of what life for each other is

like: times of frustration, times of embarrassment because our bodies act in ways we wish they did not, times when others humiliate us because our bodies do not function in patterns of convenience for them.

We both know that North Americans are socialized not to think about people with limitations. Susan Wendell (1997) notes that most buildings and activities are "structured as though everyone is physically strong, as though all bodies are *ideally shaped*, as though everyone can walk, hear and see well, as though everyone can work and play at a pace that is not compatible with any kind of illness or pain, as though no one is ever dizzy or incontinent or simply needs to sit or lie down" (p. 266). People with chronic illnesses are not always considered in social planning. Systemic barriers and lack of recognition create discrimination.

As well, North American medical practices frequently reinforce the social views of people with chronic illnesses as problematic. When illness strikes, people generally assume that it will be short term and that recovery will happen. Most of the medical profession and many individuals see illness as something to struggle against and defeat. Chronic illnesses and resulting disabilities are seen as medical failures. Too many medical professionals shame people with chronic illness by not taking symptoms seriously, by expressing anger and frustration with return visits about the same issues, or by treating "their patient" as if the individual knows nothing about her own body and what is happening to her (Taylor, with Epstein 1999: 230–232). I live with a neurological problem in my legs. For many years I went to doctors who told me that my problems did not exist or were all in my head. Neurologists typically used shame to hide their own inability to figure out what the problem was. Finally, after many tests, one doctor said, "I do not know what is wrong with you. There is something wrong and it is very hard on my ego not to be able to figure out what it is." What a relief to be in the presence of a doctor who was honest and spoke about his limits rather than blaming and humiliating me!

Obviously the experiences of people with chronic illnesses vary greatly depending on age of onset, amount and frequency of pain, support from others, and aids for daily living. Women with late-onset chronic illnesses report losses: of time and energy to do the ordinary things of life; of identity, of potential, of being able to plan a future; of friends and of involvement in community. Those diagnosed with mental illnesses also experience loss of the power to name experience, claim emotions, to have security about life. Becoming chronically ill in later life usually means loss of self-image. Hope turns to despair. For some women, new illnesses mean loss of sustaining intimate relationships. For other women, new illnesses contribute to lack of access to education and employment. Late-onset chronic illness frequently means the loss of dreams and loss of ability to take things for granted. There are losses that can never be restored. Alyshia, one of the women I interviewed, was hit by a motor vehicle while walking home from work and lives with a variety of ongoing impairments because of that accident. She describes her life-shifting losses:

> I have to accept that this is me now. It is hard. Very hard. I remember how I was ... [tears] I feel so ashamed when I don't understand. So ashamed. I have to look at people's mouths to read their lips and understand what they are saying—and it is not polite to do that. Or they talk too fast and I don't know what they are saying. I go to the doctor's every day. I have to take the special transit so it comes for me at 9:30. My appointment is done at 11, but the bus does not pick me up until 2 or 2:30—and if there are five people that they deliver, it is 5 or 5:30 when I get home. And I am so tired! (Personal interview 1997)

This woman's painful situation shows the intertwining of chronic health conditions, the loss of capacity for her to feel good about herself, and the shaming imposed on her by a society impatient with those who cannot speak or listen easily.

Shaming intends to control and disempower people. It is culturally patterned and plays different roles in different cultures. Shaming may be interpersonal (e.g., ridicule, scorn, contempt, harassment) or social and institutional (e.g., able-body bias, racism, sexism, heterosexism) (Hartling, Rosen, Walker, and Jordan 2000: 3). Since shame involves power relationships in most cases, the interstructuring of sexism, racism, classism, heterosexism, able-body bias, and other forms of violence affects who in a society is most likely to do the shaming and who is most likely to be shamed.

Much shame begins at home. In North America "dysfunctional families teach by shaming" (Bepko and Krestan 1990: 44). Shame thrives in the conflict, control, anxiety, denial, and secrecy of dysfunctional families where needs are not met and betrayals of trust occur. As girls mature, parents and peers press adolescents toward gender role

compliance. In teenage years, the desire to be liked and loved becomes paramount. Adolescent girls live in a media culture brimming with imagery of women of worth having "beautiful" non-disabled bodies. Teasing, ostracizing, and shaming isolate and silence girls who live with differences such as chronic illnesses can produce. Women who do not adopt the expected female roles to become nurturing caretakers are shamed for not knowing their place. Women with chronic illnesses often have a great deal of difficulty measuring up to the model of the perfect woman. The internalization of society's messages adds to the burden.

Moreover, shame can be both a cause and a result of mental illness, leading to devastating results. A mental health worker writes in prose poem style about one of her clients who committed suicide out of her experience of shame:

> Fiona
> Whose story of life
> Dismissed, discounted,
> Shamed
> into silence
> Crazy-fied
> How could you trust in yourself
> When you were
> Constantly berated.
> Slow wearing away of strength
> Water wearing on a stone
> Eating away at
> Fragile shoots of pride and strength
> That took hold on rocky ground.

The poem describes how "Fiona" (not her real name) was rejected in every way: as a girl, for being too noisy, for not being perfect; how she was forced to be a sexual object and told again and again to shut up. The poem goes on:

> - pressure to fit a box that didn't fit
> - being flattened by a steamroller called patriarchy
> - a steamroller called sexual abuse
> - a steamroller called medicine
> - a steamroller called psychiatry
> Your leaving
> Was testimony to the
> reality of your pain,
> A pain that could not be healed. (Personal correspondence 1997)

Unfortunately, most women with chronic mental illnesses have been taught that they are unacceptable and that their problems are their fault. Debra Connors (1985) adds, "Objectified as women and as medical, social work, and charity cases, disabled women have been deeply invalidated as human beings. We have been disabled by our society" (pp. 92–93). Women have frequently been told that our issues are in our heads not in our bodies. Dorcas, another interviewee who lives with multiple personalities, says:

> I think I gained the multiples to help me stay alive. Without my multiples, I would have gone insane. I was always aware that I had some bizarre behaviours and that I had some things that triggered me, but I did not have any idea where that came from. My power to endure came from a rebellious spark in me. (Personal interview 1997)

Paula Caplan (1991) helpfully adds:

> There can never be enough therapists to deal with the cyclone of damage being done by patriarchy and the victimization of women. Women do not have unconscious desire for suffering. Their situation causes suffering. It is not women's internal sickness. Why would psychotherapy be used to treat an epidemic? It is a social problem not an individual problem. We need a social overhaul.

Shaming disconnects women from themselves, from their real feelings, and from others. Shame puts the marginalized in a place of disempowerment and silence and keeps them there. Some women speak about their physical and mental illnesses, but those living in shame often remain wordless. The powerful in society use words to blame and misrepresent the experiences of women with chronic illnesses (especially those with mental illnesses). Those with power often want women with chronic illnesses to remain silent and act nice. Some

women can make the adaptations necessary to be nice and to fit in. If they cannot, then women are told, or come to believe, that they are worthless. They are told "that their reality is deficient or lacking. Dominant groups characteristically use shame against subordinate groups to keep them from expressing their reality in a way that would threaten the dominant view of that reality" (Hartling et al. 2000: 10). In our society, shame intends to silence the voices of those with chronic illness.

Women who normally remain silent need to find voice. As women who have had little power begin to talk about their experiences, they externalize what has been kept inside. They begin to find others who have had similar experiences. Frequently, in community women discover that what seemed to be barriers related to living with a chronic illness and/or a disability connect to issues of gender, race, class, and sexual orientation as part of the complex pattern of systemic discrimination. All are structured into a multifaceted web that intends to keep people "in their place" through shame and humiliation. Slowly women can accept that the negative self-images created by shaming, which were useful protective strategies for survival in this web, have outlived their usefulness. Shame is part of the story (i.e., something that happened), but patterns learned through shame no longer need to control reactions and life in the present. A new social construction of reality can happen. Talking about the existence of shame and about our illnesses can normalize them and lessen their power. Yet our capacity to talk about our lives depends on the day, the social and physical conditions, the power relations, the investment in the situation, its newness, how many risks we are willing to take, and how much energy we can afford to expend on educating or informing others. Drawing attention to ourselves may be more than we care to do on any given day.

Because shame cuts at the very heart of one's being, it is a deeply spiritual issue. The core of spirituality claims that each person is of worth, of infinite value in the universe, capable of being loved, and of loving. Spiritual values maintain that each person has an inherent right to be treated with respect and afforded the opportunity to live in this world with material sufficiency. The spirits of those who live with physical and mental chronic illnesses need nurturing to survive in the midst of a society constructed to deny us these rights.

To live with shame means a woman does not know in her heart of hearts that she is beloved, that she matters, and that she can love and be loved. For those who live with the consequences of shame, knowing self-acceptance in one's core presents a great challenge. Hannah struggles:

> There is a part of me that I label my "black hole." It is the place in my belly, a place I am very scared of. For ages I thought I was the only person who had this and I thought I had to keep from falling into this black hole. I would do anything to keep from being there in the pit. Talk, and then I don't have to be there. I discovered at an art workshop at least momentarily that I could connect the pit with possibilities. It is not an easy place, but now I can go there. It is, or can be, a sanctuary where I am forced to be with myself. (Personal interview 1996)

For lives and spirits to flourish, we need to be with ourselves and to know ourselves as beloved. Lewis Smedes (1993) offers hope in this way:

> Grace overcomes shame, not by uncovering an overlooked cache of excellence in ourselves but simply by accepting us, the whole of us with no regard to our beauty or our ugliness, our virtues or our vices. We are accepted wholesale. Accepted with no possibility of being rejected. Accepted once and accepted forever. Accepted at the ultimate depth of our being. (p. 108)

This knowledge is what Hannah and many other women long for.

A primary spiritual resource for many people who live with chronic illnesses is a sense of community. Shame isolates. People need to know communities of acceptance where it is clear that their illness is not a cause for shame. Elizabeth Richards (1997) states:

> I have come to believe that building friendships across the boundaries of physical and mental disability is a political act. By that I mean that friendships that truly accommodate disability fly in the face of the attempt of our society to objectify persons with disabilities.... As long as we remain objects, our society can tolerate our presence. However, should we become real, live people with interests, opinions, needs, desires, emotions or expectations, then society beware! I became committed to finding ways to be a friend and have friends. (p. 59)

As community and self-acceptance grow, the experiences of women living with chronic illnesses are named and validated. Healing from personal pain and from social injustice merge as women struggle to be free from the powers of the social construction of disability as a shameful thing. "Kendra" (a pseudonym) dreams that her life could be different:

> Social justice? To me personally it would mean many changes. It would mean members of my family would respect me as an adult, able to run my own life and take care of myself rather than exteriorizing their problems onto me and dumping them on me. Too many people in my immediate family transfer their problems to me, using my illness as an excuse. It would mean that I would receive a bona-fide mushy birthday card from at least one member of my immediate family in time for my birthday.... It means no more need to escape from reality for anyone through drugs, alcohol, etc. It means mutual supportive interaction in families, friendships, and other relationships. (Personal correspondence 1998)

Barb, a woman who lived with a chronic lung condition, takes a broader social view:

> My increasing disability means that I always understand the difference between justice and charity in new ways. I get insights that go beyond the disability. Charity too much involves the unmutual interchange that is patronizing and demeaning of the person. Justice means that it does not matter if you like the person, that they are entitled to your respect and are given some access to responsibilities. Much of our attitude toward the disabled has been charity. But I refuse to spend my life being grateful! Equal access does not mean treating everyone the same, but in allowing everyone access to the resources that they need to live. (Personal interview 1990)

Those with chronic illnesses deserve justice. As Barb notes, physical access and attitudinal acceptance for people with chronic illnesses and disability is not a matter of benevolence and goodwill, but rather a prerequisite for social justice.

Chronic illness is socially constructed. Our realities do not need to be medicalized or stigmatized. We simply need access and need our particular needs to be met. Our chronic illnesses need to be seen as ordinary parts of life, freely discussed and honestly recognized in community. We need to be seen as part of the norm—not as afterthoughts or people who need special concern nor as medical problems who should either get better or die, but as ordinary people with gifts and wisdom to share in the communities of which we are a part.

Temporarily able-bodied communities have much to learn from those of us who live with chronic illnesses. We gain insights from the diversity of our bodily and mental experiences when we are in communities that allow us to speak the truth about our lives, that enable us to participate fully and freely, and that let us know we are accepted unconditionally. Compassion and solidarity are essential; pity is not helpful.

The face of my friend Shirley dwells in my mind's eye as I write. She died several years ago of a stroke, the result of kidney failure and diabetes. Her life was full of pain, fear, and despair. She would get angry with people who said to her, "Oh I don't know how you do it! I just don't know how you keep on going." Her response became "What choice do I have? Life goes on. The sun rises, the sun sets, and I am still alive." It was not glorious and heroic. But the sun rose and the sun set. And there were few choices.

The sun rises again and again without grace for many people with chronic illnesses. When transcendence comes, it is a gift, but if we expect to know hope, goodness, or holiness in suffering in some special way, we may be greatly disappointed. Transcendence, hope, and spiritual presence are not unique gifts given to those who suffer. They may come, but more often the sun rises, the sun sets. We are invited to face pain, fear, rage, shame, despair, and sometimes death, and to live with as much courage and love as we can muster. In a world that focuses on power, prestige, and acquisition of goods, learning how to live with loss, with chronic illness, and with the results of shaming are needed for healthy and inclusive communities, and so we work and long for transformation toward a new politic with sharing of power, the equitable distribution of resources, and life without shaming for all.